

## Working Group to Develop a State Plan for Alzheimer's Disease and Related Disorders

### Caregivers Sub-Group

#### Minutes

#### *First Meeting*

10/11/12

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**Attendees:** Kathy McKeon (chair, Diocese of Providence), Susan Saccocia-Olson (BCBSRI), Karen Proffitt (Visiting Angels), Cynthia Conant-Arp (Hope Alzheimer's Day Center), Valerie Topp (Home Instead Senior Care), Camilla Farrell (Alzheimer's Association of RI), Joan Kent (Alzheimer's Association of RI), Catherine Desautels (NHPRI), Lindsay McAllister (Office of the Lt. Governor).

1. Kathy McKeon, who will serve as chair of the sub-group, provided an introduction to the group and asked everyone to introduce themselves.
  - a. Diocese has had a Respite Program for 20 years and has been funded through DEA over the last several years to provide respite to caregivers of persons 60 years of age or older, or persons with Alzheimer's disease of any age. They often have a waiting list. Many times they start the year with a waiting list. This is the case even with very little outreach. They send a few notices here and there, but not much. Caregiving has become a truly universal experience. We are the state with the highest population over 85. We really want to build upon what is already underway and not just repeat work.
  - b. **Lifespan/Respite** funding was awarded to RI three years ago. RI was one of the first states to receive a planning and systems grant. The new 18 month Life Span Respite grant, awarded in August, will allow a continuation of systems work as well as service expenses. These funds can be used to help caregivers caring for a disabled child, a disabled adult child, or an elder. The point is to wrap around the pots of service and get towards a more holistic approach.
  - c. **CareBreaks** is the new name for the Diocese Respite Care Program. – for caregivers caring for a disabled family member of any age. They provide help to low-income people unable to pay for a break but also hoping to gain volunteers in order to broaden that assistance. Training will need to be part of this – a volunteer with some training if they don't have a medical background. Often if working with a child with disability, their care is very technical and complicated.
  - d. Another effort is to map existing services across the state and this will be included as part of a gap analysis the Diocese is working on – their goal is to identify anything that is not available or isn't working as it needs to. For example, if a family is eligible for respite, yet cannot find a person who is able to meet their particular need. They'll be contacting 2-3 of the national organizations doing work in this area to find out where there's a model that is working and is innovative that we can use to inform this process in RI.

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- e. On the Medicaid front, Money Follows the Person (MFP) is an effort geared toward nursing home discharge and has a goal of transitioning 500 people over the next three years (Rhodes to Home). "Home" can be an assisted living home or supervised/shared living. Part of this program is to develop some of those gap-filling resources that will enable people to leave institutional environments and live safely and successfully in the community.
2. Lindsay McAllister provided an overview of the entire Alzheimer's State Plan process, including a description of how the Joint Resolution, which created this Working Group, came about, a review of the past few meetings of the full group, the goals of this first State Plan, and an overview of the work plan for the group.
3. The group then went over the charge given to this Caregivers Sub-Group and discussed each piece to determine if any changes should be made.
4. Adult Day Care, Respite Care and Employee Support Services:
  - a. In the past children needing **residential placement** were able to obtain a placement in the Tavares Center under Medicaid. This service is no longer covered. Overnight placement for disabled children is a gap in service.
  - b. The National Alliance for Caregivers and the Administration on Aging both serve as good resources.
  - c. **Lindsay will look into whether the AOA have any ongoing demonstration projects on family supports and report back to the committee.**
  - d. Cynthia mentioned a Woonsocket Adult Day Center that does weekend programming. There are a few models we should look at, for example, a Jewish home in the Bronx that does overnight "day care." **Lindsay will bring information on this model back for further discussion.**
  - e. Susan brought up the **need for nurse coordinators** to help families and individuals through the system. This is part of the benefit BCBSRI provides. Nurse Care Coordinators, covered by insurance, help to connect caregivers to resources and just to have someone to talk to about what is going on and how things are progressing.
  - f. Cynthia – There are also some caregiver supports provided over the phone, funded by NIH and run through Dr. Jeff Tremont (Care Reassurance Program). This is a **telephone coaching program**.
  - g. Valerie mentioned the work of large corporations providing Employee Assistance Programs (EAPs) in RI that can reach a lot of families. She met with one of the EAPs and it was an hour of questioning with their staff – often the families want the information and don't have it.
  - h. **The group agreed that employee support services may already be dealing with caregiving – potentially through "brown bag lunches" and this would be a starting point for a potential recommendation.**

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- i. **Informal Community Supports** – The group felt this topic was just as important as respite and adult day. For the caregiver to be able to talk to someone and go through what the experience is like for them is huge. **The Alz. Association has a program on this.**
- j. Cynthia brought up the importance of a training program or some sort of resource that could teach the skills to avoid crises.
- k. Catherine agreed and that they'd had a 60 bed unit yet the level of **education is lacking – not just with caregivers and families but also with staff.** People don't know or understand how to deal with individuals with dementia. The appropriateness of how you deal with and handle/communicate with Alzheimer's individual versus another type of patient is complicated. **This is worsened by the use of temporary staffing on the weekends that are not often trained to know how best to deal with them.** Even if you take the Alzheimer's class you aren't necessarily prepared. Hospitals are traumatic places – **the transition alone – is enough to really overwhelm someone.** From long-term care to a hospital is traumatic.  
**There are so many educational resources; Alz association, Home Instead, Cornerstone, Visiting Angels all provide education. Respite care is usually provided at the same time so caregivers can attend.**
- l. The physicians also need education! But this piece is tough because people are scared of offending their doctors and families shy away from getting a second opinion, yet they really should. **Education is needed around how to speak to your doctor about wanting a second opinion.**
- m. Karen Proffit mentioned the need for a tool such as a checklist. This is an emotional process and there needs to be someone to reach out to: primary care doctors with training, specialists, Alz. Assoc., etc.).
- n. **Do these tools exist? If not, we could recommend. The sub-group needs more information on this.**
- o. **The group felt that generally, we have the key things here. Finding out what is available, finding the gaps, getting suggestions from other states as to how to fill them, looking at it all from cultural diversity and different cultural understanding, different view points of those who have family vs. those who are alone, how to avoid waiting too long for respite care and other services.**
- p. Susan shared that she did Dr. Stopa's plan with her mother and it gave her major comfort to know her death was not in vain – emphasize that this can be comforting – something directed at families about end of life and guiding them about what they can do...guides to tissue donation and clinical trials are needed.
- q. **The group seemed to agree that this is important: De-mystifying the clinical trials process: what do they need to hear? Where do they want to hear it? How? What sells this idea to families and loved ones.**
  - i. What can we learn from the polio vaccine – the urgency that was expressed to find a vaccine, the quick results, how the public

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education process worked? It got out so fast to families – how did they accomplish that?

- r. Valerie continued, clinical trials allow families to get additional support like social workers and medical check-ins. These programs can be similar to a hospice program. Valerie handed out a pamphlet on participating in the clinical trial with PREVENT Alzheimer's disease.
- 5. If you think of someone who might be a great addition to the group please bring them or let Kathy know and she will reach out to them. Also feel free to suggest a particular program to discuss.
  - a. Cynthia suggested that quality of life measures was not included in the National Alzheimer's Plan and it belongs in our plan. It fits in this subgroup because Alzheimer's is really a family disease.
- 6. Overview of Current Services by Camilla Farrell, RI Chapter of the Alzheimer's Association:
  - a. Camilla works for the Association and is a caregiver herself. They provide services and promote brain health. They exist on behalf of the 24,000 RI'ers with the disease and as many as 100,000 caregivers.
  - b. People are being diagnosed earlier and younger. Live and Learn includes people in their 40's. These younger folks are willing to speak out, fundraise, etc. This has been really encouraging.
  - c. A hotline, counseling, caregiver education and a trial match program (matches people with clinical trials – the “dating service.”) are all part of what they do. There's also an 800 number, medical alert and safe return program, caregiver conference (free to caregivers because of funding from DEA and the Diocesan grant), a free research lecture, advocacy and programs
  - d. Joan spoke about the helpline. It is mostly people who call looking for information but they also want to talk. If you suggest you've been through it as well there is a real connection.
  - e. Care consultation is free and often it's the family dynamics (family members disagree).
  - f. Support Groups, are offered through the Association, as are facilitator trainings.
  - g. Patient Education is mostly focused around “knowing the ten warning signs.”
  - h. Live & Learns is for people in the early stages – go for 2 hours and exercise, go on a trip, and the caregiver can have respite. This was originally a grant through DEA and now it's sustained on its own. Members get involved in fundraising and volunteering.
  - i. Caregiver Education Programs – Carefinder is web-based service offered by national association.
  - j. Medical Alert – Safe Return: small fee but offers peace of mind.
  - k. Senior Housing Finder is another service offered (more information available in a packet available through the Association).
  - l. Lunch and Learns provide education and training in the workplace (about 20/year).

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- m. Trial Match for clinical studies.
  - n. Annual Free Conference and a Research-focused Lunch.
  - o. Professional Training – employees get trained for management
  - p. They also offer information about handling the dual diagnosis of Alzheimer's disease and Downs Syndrome.
  - q. Train the Trainer programs are also available.
7. Camilla estimated that they touch over 10,000 people annually (through helpline at least a 1,000).
  8. Valerie asked to add early onset Alzheimer's caregivers because often available services aren't appropriate for the younger patients and there are no programs or financial support for them.
  9. **Kathy McKeon mentioned that a kidney dialysis diagnosis fast-tracks you to Medicaid eligibility. It would often get triggered once they could no longer work. This could be something to look into for younger patients with Alzheimer's disease.**
  10. Camilla and Joan mentioned that someone in Live and Learn had a husband go through disability determination (SSDI) – but this can be a year or 2 year process because nearly all get denied the first time. This process can require an SSI lawyer, court, dates in court, etc. Hoops are designed to discourage people. Often it's an elderly spouse and there's no way they have the stamina to persevere through the application process.
  11. The meeting was adjourned.

**Next Meeting November 7, 2012 2:00 PM at One Cathedral Square**